

Caregiver Stress and the Benefits of Obtaining Support

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Family caregiving can span many years depending on the stage of illness, progression of deterioration, and the family's resources for managing the needs of the person with Alzheimer's disease (AD).

Caregiver stress and negative health outcomes are common. Although most caregivers can manage the day to day practical aspects of caregiving during the early impairment stages of AD, caregiver stress levels escalate as the disease progresses. With the onset of unrelenting stress caregivers are most vulnerable for developing physical and mental health problems. Also, as the disease progresses caregivers experience an increasing sense of loss and mourning due to dramatic changes in the care recipient's personality and behavior – the person ceases to be the person they have known over a large part of their lives together.

Spouses lose their companions where reciprocity was the norm and assume instead the care of a now dependent family member.

It is understandable that most caregivers need practical and emotional support to manage caregiving tasks and look to family and friends for ongoing support. However, studies show that many caregivers feel isolated and are reluctant to ask family and friends for help. Others live at some distance from family members and thus cannot depend on their practical help and support. Community-based support groups for AD caregivers such as those provided by Alzheimer Societies across Canada can provide much needed information about AD, its treatment, and emotional empathic support. Studies of support groups for AD caregivers show that they are helpful

in reducing the stress of caregiving. Other community support programs such as in home or institutional respite care are very helpful in relieving caregiver stress and burden.

Because some caregivers live in remote areas and others cannot leave the care recipient in order to attend a support group, e-health programs can provide support to caregivers in their own homes. At Baycrest we have developed and evaluated an Internet-based caregiver support program for AD caregivers with promising results. We designed a user friendly web site that links caregivers to information about AD and guidelines for caregivers



to take care of themselves so as to avoid health problems and caregiver burnout. Groups of six caregivers log onto a password-protected website and access a video conferencing link to join a support group facilitated by a health professional weekly for ten sessions. Feedback from the participants has been very positive. Analysis of follow up interviews showed lower levels of stress in caregivers who participated in the online groups when compared with caregivers who did not access a support group.

Our chapter's thanks to the local caregivers who participated in the above mentioned internet-based support program study.